

End of Life, Withdrawal, and Palliative Care Utilization among Patients Receiving Maintenance Hemodialysis Therapy

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Abstract

Background and objectives Withdrawal from maintenance hemodialysis before death has become more common because of high disease and treatment burden. The study objective was to identify patient factors and examine the terminal course associated with hemodialysis withdrawal, and assess patterns of palliative care involvement before death among patients on maintenance hemodialysis.

Design, setting, participants, & measurements We designed an observational cohort study of adult patients on incident hemodialysis in a midwestern United States tertiary center, from January 2001 to November 2013, with death events through to November 2015. Logistic regression models evaluated associations between patient characteristics and withdrawal status and palliative care service utilization.

Results Among 1226 patients, 536 died and 262 (49% of 536) withdrew. A random sample (10%; 52 out of 536) review of Death Notification Forms revealed 73% sensitivity for withdrawal. Risk factors for withdrawal before death included older age, white race, palliative care consultation within 6 months, hospitalization within 30 days, cerebrovascular disease, and no coronary artery disease. Most withdrawal decisions were made by patients (60%) or a family member (33%; surrogates). The majority withdrew either because of acute medical complications (51%) or failure to thrive/frailty (22%). After withdrawal, median time to death was 7 days (interquartile range, 4–11). In-hospital deaths were less common in the withdrawal group (34% versus 46% nonwithdrawal, $P=0.003$). A third (34%; 90 out of 262) of those that withdrew received palliative care services. Palliative care consultation in the withdrawal group was associated with longer hemodialysis duration (odds ratio, 1.19 per year; 95% confidence interval, 1.10 to 1.3; $P<0.001$), hospitalization within 30 days of death (odds ratio, 5.78; 95% confidence interval, 2.62 to 12.73; $P<0.001$), and death in hospital (odds ratio, 1.92; 95% confidence interval, 1.13 to 3.27; $P=0.02$).

Conclusions In this single-center study, the rate of hemodialysis withdrawals were twice the frequency previously described. Acute medical complications and frailty appeared to be driving factors. However, palliative care services were used in only a minority of patients.

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Introduction

Maintenance hemodialysis (HD) therapy is now provided to over 440,000 patients annually in the United States (1). Patients on maintenance HD have a high prevalence of debilitating symptoms (2), and their long-term prognosis is guarded, with a life expectancy of less than a third to half that of the general age-matched population (3). For patients with ESKD, palliative care consultative services may improve quality of life by aiding in symptom management in addition to aligning patient preferences and goals of care, but it is underutilized in this population (4–7). Despite a poor prognosis, the overwhelming majority (>80%) of patients on dialysis are hospitalized and receive intensive care unit treatment (>60%) in the last 90 days of their life and less than a third receive

hospice services (8). The current treatment practices at end of life may not reflect patient wishes. In a United States study examining advance care planning in patients on maintenance HD, only 18% preferred to live as long as possible despite suffering (9). In a survey of patients with CKD in Canada, 36% preferred to die at home or in an inpatient hospice (29%) rather than in a hospital (27%) (10). This contrasts starkly with the current reality of end-of-life care for patients on dialysis, which is more aggressive than that for other life-limiting diseases (5,11,12).

Withdrawal from dialysis therapy is reported as a cause of death in 20%–30% of ESKD patients in Western countries (1,3,13). Several studies assessed HD withdrawal rate and factors associated with withdrawal using administrative claims data or death

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notifications (1,3,13–15). Yet, the reported withdrawal rates may be underestimated given (1) changes in coding recommendation for withdrawal cause of death, and (2) varied guidance as to what constitutes death preceded by HD withdrawal. Thus, more granular information is needed regarding the true prevalence of HD withdrawal, the terminal course after withdrawal, and the utilization of palliative care services. Gaining a more thorough understanding of these factors can help facilitate timely goals-of-care discussions between clinicians and patients to better meet patient preferences and ultimately improve end-of-life care for patients with ESKD (16). Therefore, the goal of this study was to examine the frequency of HD withdrawal before death, patient factors associated with withdrawal, terminal course after withdrawal, and patterns of palliative care involvement before death among patients on maintenance HD treated in an integrated health care network utilizing an integrated electronic medical records system.

Materials and Methods

Study Population

Patients included in the study were individuals aged ≥ 18 years who initiated maintenance HD from January 9, 2001 to November 15, 2013 at Mayo Clinic Dialysis Services ($n=1226$). Mayo Clinic Dialysis Services provides all HD in an integrated health care network for residents in southeastern Minnesota, northern Iowa, and southwestern Wisconsin, through eight community-based outpatient HD facilities as previously described (17–19). The study population was restricted to 590 patients who died before study end on November 15, 2015. Patients were excluded if they received HD for <30 days ($n=30$), transferred care outside of the network ($n=23$), or transitioned to peritoneal dialysis ($n=1$) before study end. Minnesota research authorization was available for the final study cohort ($n=536$). The study was reviewed and approved by the Mayo Clinic Institutional Review Board (IRB#09-007581).

Electronic medical records were reviewed for cause of kidney disease, patient comorbidities, reason for HD withdrawal, date, cause and location of death, number of hospital admissions within 30 days before death, and presence and timing of palliative care consultation before death. To compare HD withdrawal reporting patterns from our institution and withdrawal status identified in this study, we obtained Centers for Medicare and Medicaid Services (CMS)-2746 ESKD Death Notification Forms from CROWNWeb (20,21), on a random sample comprising 10% ($n=52$) of the death cohort, 26 from the withdrawal and 26 from the nonwithdrawal cohort. If the cause of death was not primarily identified as HD withdrawal, the CMS-2746 primary cause of death was recorded. Electronic medical records and CMS-2746 forms were reviewed by physicians (J.C.-Y.C. and L.J.H.) and/or trained nurse abstractors.

Definitions

HD withdrawal was defined as HD discontinuation after an active decision to permanently stop dialysis by the patient, family, health care power of attorney, or health care team, as documented in the electronic medical record. Death after dialysis withdrawal was defined as a death event occurring >24 hours after HD withdrawal. These

criteria were used to exclude patients in which HD withdrawal was undertaken in the context of withdrawal of other life-sustaining treatments in the face of impending and/or immediate death. Reason(s) for HD withdrawal were categorized as recommended by CMS-2746 form and Murphy *et al.* (22): (1) HD access failure, (2) acute medical complications, (3) chronic debilitating problems, (4) chronic failure to thrive/frailty, and (5) kidney withdrawal. Kidney withdrawal was defined per Murphy *et al.* as death preceded by HD withdrawal primarily related to kidney dysfunction/uremia without significant medical problems other than kidney failure. Acute medical complications and chronic debilitating problems were further categorized into specific clinical conditions, including cardiac disease, lung disease, malignancy, resistant infection or sepsis, multiple comorbidities leading to poor prognosis, and other. Palliative care consultative services were noted if care from a palliative care team member was documented in either the inpatient or outpatient setting within 6 months of death. Missing data for death location was assigned to the 'unknown' category.

Statistical Analyses

Continuous variables are reported as mean with SD or median with interquartile range (IQR) for non-normally distributed variables. Categorical variables are expressed as number (percentage). Comparisons between withdrawal and nonwithdrawal groups, as well as those with and without palliative care among patients who underwent withdrawal, were made using univariable and multivariable logistic regression models. No data were missing for the univariable and multivariable analyses. P values <0.05 were considered statistically significant. Analyses were performed using SAS 9.4 (SAS Institute, Inc., Cary, NC) and R software v3.4.1.

Results

Death Cohort and HD Withdrawal

Among 1226 patients receiving incident HD at Mayo Clinic Dialysis Services, 536 (44%) died within the study period. Of these, 262 (21% of the original cohort and 49% of the death cohort) withdrew from HD before death. Patient characteristics are shown for the death cohort ($n=536$; Table 1). Overall, mean patient age at start of dialysis was 72 (SD 13) years and 74 (SD 13) years at time of death. A majority of the cohort were men (60%) and white (94%). Common comorbidities included congestive heart failure (70%), coronary artery disease (67%), and diabetes mellitus (59%). Diabetic kidney disease was the most common cause of CKD (37%), followed by hypertension (20%). The median HD duration was 23 months (IQR, 8–47) with 68% having at least one hospitalization within 30 days of death and 26% having a palliative care consultation within 6 months of death.

Factors Associated with HD Withdrawal

The odds of withdrawal from HD therapy before death were higher in patients who were older at HD initiation (odds ratio [OR] per 10 years, 1.30; 95% confidence interval [95% CI], 1.12 to 1.49; $P<0.001$), of white race (OR, 2.19; 95% CI, 1.05 to 4.57; $P=0.04$), with a history of

cerebrovascular disease (OR, 1.59; 95% CI, 1.13 to 2.26; $P=0.01$), and without a history of coronary artery disease (OR, 0.60; 95% CI, 0.42 to 0.87; $P=0.01$). Median HD duration did not differ between groups. However, the odds of withdrawal were higher in those with a hospitalization within 30 days of death (OR, 1.65; 95% CI, 1.15 to 2.39; $P=0.01$) and palliative care consultation within 6 months of death (OR, 2.29; 95% CI, 1.54 to 3.40; $P<0.001$) compared with those without. Results were similar after fitting multivariable models using all characteristics in Table 2 (Supplemental Table 1).

Reasons for HD withdrawal before death are presented in Figure 1A. The most common reasons for withdrawal were acute medical complications (51%), failure to thrive/frailty (22%), and chronic debilitating problems (18%). Only one individual withdrew from HD because of exhaustion of dialysis access sites and options for kidney replacement therapy (0.4%). Among those with acute medical complications or chronic debilitating problems leading to HD withdrawal, multiple comorbidities leading to poor prognosis was most commonly identified as a contributing factor (Figure 1B). In the withdrawal group, an active decision to withdraw was made by 156 (60%) patients themselves. Approximately one third of withdrawal decisions were made by surrogates: in 91 (35%) patients, the decision was made by family, in seven (3%) patients, it was made by nonfamily power of attorney, in five (2%) patients, the decision was made by the health care team, and the remaining three (1%) were unknown.

To assess the frequency of HD withdrawal reporting on the basis of our Death Notification Forms as compared with our current medical record review, a random sample of the withdrawal cohort was queried for CMS-2746 ESKD Death Notification Forms. Of the 52 patients (comprising 10% of the final cohort: 26 patients each from withdrawal and nonwithdrawal cohorts), seven patients in the withdrawal cohort had a nonwithdrawal primary cause of death listed on the death form. These nonwithdrawal primary death causes included chronic obstructive pulmonary disease, pulmonary infection, myocardial infarction, pulmonary edema, septicemia, dementia, and malignancy. The sensitivity of the Death Notification Form for withdrawal is 73%, the specificity is 100%, the positive predictive value is 100%, and the negative predictive value is 79%.

Terminal Course after HD Withdrawal

Care settings at the time of death are illustrated in Figure 2. Nearly half (46%) of the patients who did not withdraw from HD before death died in the hospital, primarily in the intensive care unit setting. Conversely, fewer patients who did withdraw from HD died in the hospital (34%; $P=0.003$), with a minority dying in the intensive care unit setting. Hospice care at the time of death was provided to 22% of the entire death cohort, although more commonly provided in patients who withdrew (37% versus 7% nonwithdrawal; $P<0.001$). After HD withdrawal, the median time to death was 7 days (IQR, 4–11), with 183 (70%) deaths in <10 days, 72 (28%) deaths between 10 and 30 days, five (2%) deaths between 30 and 100 days, and two (1%) deaths in over 100 days (Figure 3). The two patients with prolonged survival (>100 days) after HD withdrawal had substantial residual kidney function.

Table 1. Patient characteristics among patients on hemodialysis who died between 2001 and 2015 ($n=536$)

Characteristics at Baseline and Death	Cohort, $n=536$
Baseline characteristics	
Age at HD initiation, mean (SD)	72 (13)
HD duration, mo, median [IQR]	23 [8–47]
Men, n (%)	321 (60)
White, n (%)	501 (94)
Cause of ESKD, n (%)	
<i>Polycystic kidney disease</i>	9 (2)
<i>Diabetic kidney disease</i>	199 (37)
<i>Hypertension</i>	109 (20)
<i>Glomerular/tubulointerstitial disease</i>	64 (12)
<i>Acute tubular necrosis</i>	19 (4)
<i>Failing kidney transplant</i>	25 (5)
<i>Other</i>	89 (17)
<i>Unknown</i>	22 (4)
Comorbidities and characteristics at death, n (%)	
Congestive heart failure	375 (70)
Coronary artery disease	358 (67)
Valvular heart disease	270 (50)
Diabetes mellitus	314 (59)
Malignancy	187 (35)
Cerebrovascular disease	213 (40)
Liver disease	67 (13)
COPD	168 (31)
Peripheral vascular disease	242 (45)
Depression	223 (42)
Hospitalization before death ^a	363 (68)
Palliative care consultation before death ^b	141 (26)
Age at death, mean (SD)	74 (13)
HD, hemodialysis; IQR, interquartile range; COPD, chronic obstructive pulmonary disease.	
^a Hospitalizations were included if they occurred ≤ 30 days before death.	
^b Palliative care consultations were included if they occurred ≤ 6 months before death.	

Palliative Care Utilization in the Withdrawal Cohort

In the HD withdrawal group, approximately one third (34%; 90 patients) received palliative care consultative services within the 6 months preceding death, and 68% of the initial consultations occurred in the hospital. Reasons for palliative consultation included facilitation of withdrawal decisions (54%), end-of-life care options or hospice enrollment (19%), a prospective pilot palliative project in patients with ESKD (23) during the study period (16%), symptom management (9%), and other (2%). The median number of palliative visits per patient conducted in this 6-month period was 3 (IQR, 1–23). The odds of receiving palliative care consultation within 6 months of death were higher among those with longer HD duration (OR per year, 1.19; 95% CI, 1.08 to 1.31; $P<0.001$), hospitalizations within 30 days of death (OR, 5.78; 95% CI, 2.62 to 12.73; $P<0.001$), and those who experienced in-hospital death (OR, 1.92; 95% CI, 1.13 to 3.27; $P=0.02$; Table 3). Results were similar after fitting multivariable models using all characteristics in Table 3 (Supplemental Table 2).

Discussion

In this incident, single-center, cohort study, nearly half (49%) of all deaths occurred after HD withdrawal. This rate

Table 2. Patient characteristics associated with withdrawal from hemodialysis before death, among patients (n=536) who died between 2001 and 2015

Characteristics at Baseline and Death	No Withdrawal, n=274	Withdrawal, n=262	Withdrawal Odds Ratio (95% CI)	P Value
Baseline characteristics				
Age at HD initiation, mean (SD)	70 (13)	74 (12)	1.30 (1.12 to 1.49) ^a	<0.001
HD duration, mo, median [IQR]	22 [8–45]	24 [7–49]	1.04 (0.97 to 1.12) ^b	0.25
Men, n (%)	174 (64)	147 (56)	0.74 (0.52 to 1.04)	0.08
White, n (%)	250 (91)	251 (96)	2.19 (1.05 to 4.57)	0.04
Cause of ESKD, n (%)				0.36
<i>Polycystic kidney disease</i>	6 (2)	3 (1)	Reference	
<i>Diabetic kidney disease</i>	98 (36)	101 (39)	2.06 (0.50 to 8.47)	
<i>Hypertension</i>	54 (20)	55 (21)	2.04 (0.49 to 8.56)	
<i>Glomerular/tubulointerstitial disease</i>	27 (10)	37 (14)	2.74 (0.63 to 11.94)	
<i>Acute tubular necrosis</i>	12 (4)	7 (3)	1.17 (0.22 to 6.20)	
<i>Failing kidney transplant</i>	16 (6)	9 (3)	1.13 (0.23 to 5.62)	
<i>Other/unknown</i>	61 (22)	50 (19)	1.64 (0.39 to 6.89)	
Comorbidities and characteristics at death, n (%)				
Congestive heart failure	195 (71)	180 (69)	0.89 (0.62 to 1.29)	0.53
Coronary artery disease	198 (72)	160 (61)	0.60 (0.42 to 0.87)	0.01
Valvular heart disease	129 (47)	141 (54)	1.31 (0.93 to 1.84)	0.12
Diabetes mellitus	170 (62)	144 (55)	0.75 (0.53 to 1.05)	0.10
Malignancy	87 (33)	100 (38)	1.33 (0.93 to 1.89)	0.12
Cerebrovascular disease	94 (34)	119 (45)	1.59 (1.13 to 2.26)	0.01
Liver disease	33 (12)	34 (13)	1.09 (0.65 to 1.82)	0.74
COPD	84 (31)	84 (32)	1.07 (0.74 to 1.54)	0.73
Peripheral vascular disease	127 (46)	115 (44)	0.91 (0.64 to 1.27)	0.57
Depression	104 (38)	119 (45)	1.36 (0.96 to 1.92)	0.08
Hospitalization before death ^c	171 (62)	192 (73)	1.65 (1.15 to 2.39)	0.01
Palliative care consultation before death ^d	51 (19)	90 (34)	2.29 (1.54 to 3.40)	<0.001

P values <0.05 were considered statistically significant and are denoted in bold. P values were derived using logistic regression models. 95% CI, 95% confidence interval; HD, hemodialysis; IQR, interquartile range; COPD, chronic obstructive pulmonary disease.

^aPer 10 years.

^bPer year.

^cHospitalizations were included if they occurred ≤30 days before death.

^dPalliative care consultations were included if they occurred ≤6 months before death.

is almost double that previously reported (1,3,13) in Western countries. We also found that patients who were older, white, with recent hospitalization, prior cerebrovascular disease, and no cardiovascular disease were more likely to withdraw. Acute medical complications were driving factors for withdrawal. Finally, a minority (one third of patients) who withdrew received palliative care services within 6 months of death. Our study provides insight into the clinical context of HD withdrawal, suggesting that a patient who is more likely to withdraw from HD is an elderly individual with multiple comorbidities who develops an acute medical complication with limited treatment options, leading to the decision to withdraw. These results highlight the need to proactively identify patients on HD with limited prognoses and high symptom burden (24) who could benefit from earlier palliative care services and advance care planning before a hospitalization event.

Although our findings overlap with those of other studies on HD withdrawal, there are some key differences. We utilized the narrative medical records to define HD withdrawal and required documentation of an active decision to permanently discontinue HD by patient, family, health care power of attorney, or health care team. Similar

studies were done in the first two decades of dialysis treatment in the United States and were largely focused on describing rates of withdrawal by cause of ESKD and dialysis modalities (14,15). More recent studies based their definition of dialysis withdrawal on registry data (1,3) or death notifications (1,25), which may be limited by reporting consistency over time or changes in withdrawal definitions and therefore underestimate the withdrawal rates. Historically, there is also international variation in the classification of withdrawal (22). In the United States, the CMS-2746 ESKD Death Notification Form has undergone periodic revisions, with “withdrawal from dialysis/uremia” added as a cause of death in 2004. Moreover, the Australia and New Zealand Dialysis and Transplant registry has broad categories of cause of death, including cardiac, vascular, infection, and social, wherein dialysis withdrawal is housed in the social category (3). Finally, variability within a single institution may be seen over time. In a small (n=52) random sampling of the death cohort, we identified differences between our CMS-2746 ESKD Death Notification Form reporting and our study reviews of withdrawals (73% sensitivity for withdrawal). Collectively, these findings support the notion of potential discrepancies between abstracted HD withdrawal rates

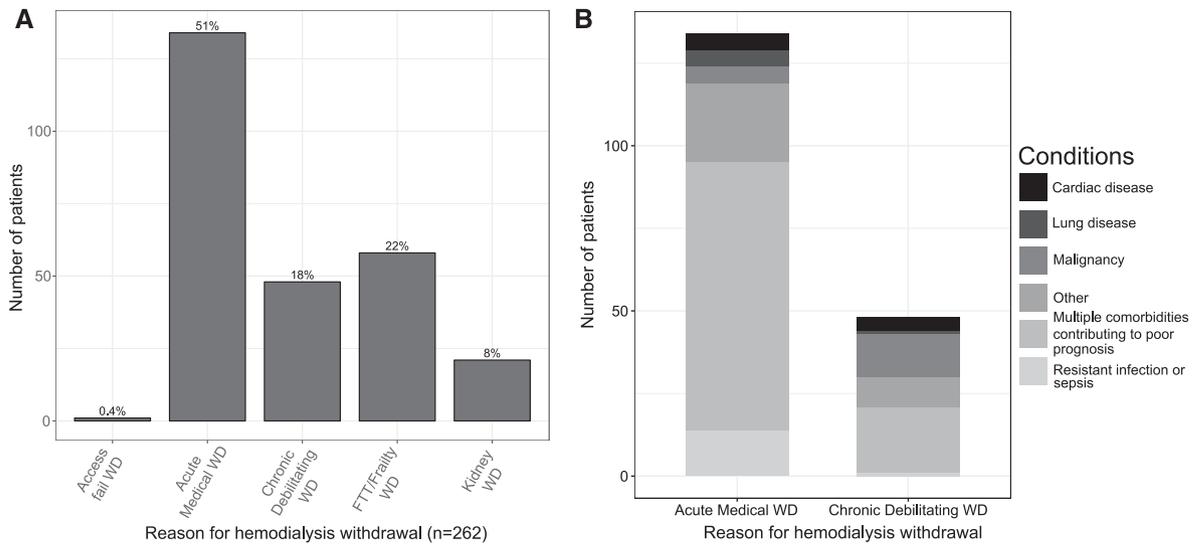


Figure 1. | Acute medical complication was the most common reason for HD withdrawal. (A) Reasons for HD withdrawal before death on the basis of categories by Murphy *et al.* (22) (n=262). (B) Conditions contributing to acute medical and chronic debilitating HD withdrawal reasons. FTT, failure to thrive; WD, withdrawal.

from registry data and the narrative medical records on a broader scale, due to a variety of factors.

There is an increasing interest in end-of-life care in patients with ESKD, and guidelines and communication frameworks have now been developed to facilitate shared decision-making (26,27). To involve patients and family in the decision-making process, advance care planning needs

to be regularly discussed and initiated early in the disease course (28). Unfortunately, advance directives are underutilized in this population and largely devoid of references to dialysis preferences (16,29). In previous studies looking at withdrawal decision-making, there was a high proportion of cases needing surrogates or physicians to make end-of-life decisions (30,31). In our study, most withdrawal

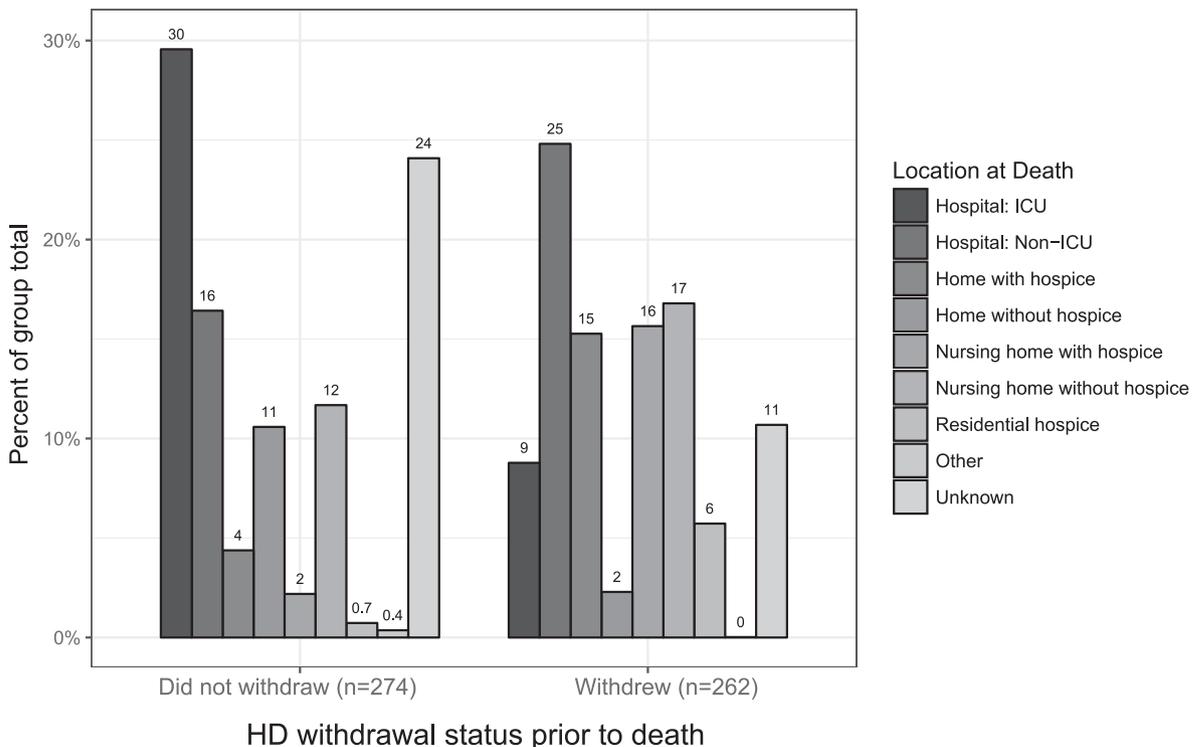


Figure 2. | More patients on HD without withdrawal died in a hospital setting. Care settings at time of death by percentage in patients on HD with (n=262) and without (n=274) HD withdrawal before death. ICU, intensive care unit.

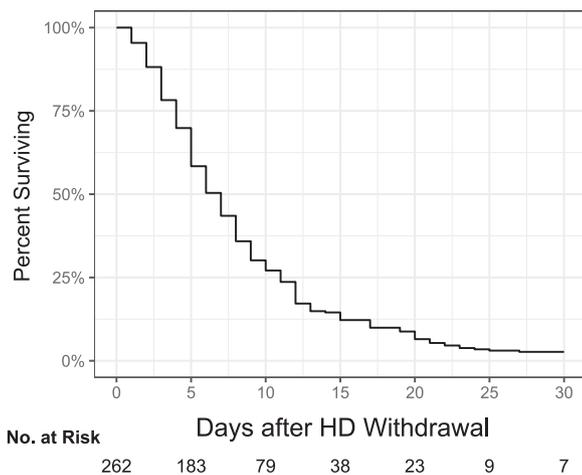


Figure 3. | Most patients on HD that withdrew died within the first two weeks. Patient survival in days after final dialysis session in patients on HD who withdrew from dialysis therapy and died ($n=262$).

decisions were made by the patients (60%), followed by family members (33%), and the most common reason for withdrawal was acute medical complications (51%). Similar to other studies, we found that most (70%) patients who underwent HD withdrawal died within 10 days of HD withdrawal and died in a nonhospital setting (66%) (1,32–34). The decision of HD withdrawal is complex (35). Knowing what to expect after HD withdrawal and identifying the signs of deterioration (acute or chronic medical complications, such as frequent hospitalizations) can help patients and their surrogates make informed decisions.

In this study, about one third (34%) of the withdrawal cohort had palliative care involvement within 6 months before death and less than a quarter (22% of total death cohort) utilized hospice services, which is higher than previously reported (1,7,36). Although 37% of the withdrawal cohort utilized hospice at the end of life, 40% died in the hospital setting after HD withdrawal, reflecting the high percentage of early deaths after withdrawal. In general, palliative and hospice services have been underutilized in the ESKD population compared with that of patients with cancer, despite the high mortality and morbidity of patients with ESKD (35). Among patients who died in inpatient facilities in the Veteran Affairs health care system, only half of patients on ESKD received palliative care services compared with almost three quarters of patients with cancer (5). This underutilization may be because of the uncertainty of disease trajectory for patients with ESKD (37,38) and inadequate training in end-of-life care in nephrologists (39,40). In addition, the requirement of foregoing dialysis to qualify for the hospice Medicare benefit, unless the patient has a second terminal diagnosis unrelated to kidney failure, may contribute to the low rate of hospice enrollment (or utilization) for patients with ESKD (38). Moreover, although our institution benefits from an outpatient palliative care clinic offering services to patients on HD, studies suggest that fewer than 20% of institutions have outpatient palliative care services available (41), making inpatient palliative care consultation the only option for the majority of patients.

Therein, limited access to palliative care may be another barrier contributing to low rates of palliative care consultation and/or hospice utilization. Overall, these important findings suggest that detailed reviews of individual patient experiences may be necessary to determine the true rate of deliberate HD withdrawal before death and the need for palliative and hospice services to support these individuals at the end of life.

This study has limitations. First, the vast majority (94%) of the cohort was white, which is not reflective of the ESKD population in the United States, wherein ethnic and racial minorities are over-represented (8). White race has been associated with HD withdrawal (3,25,42), and this may have contributed to our higher withdrawal rate. Second, we studied United States patients from a single tertiary center, which may reflect practice biases and further limit generalizability to other populations. Third, we did not review individual patient preferences and goals in this study which represents an important future area for research. Lastly, our rate of palliative care consultation might be higher as 14 patients were part of the palliative care pilot project (23), which was the third most common reason for palliative care consultation. However, the single integrated system allowed for a unified definition of HD withdrawal and granular detailed abstraction of individual patient information, rather than diagnostic/administrative billing codes or death certifications, which may lack accuracy.

In conclusion, medical record–abstracted HD withdrawal at our center was nearly double that previously reported in the literature, suggesting that large registry data may underestimate the rate of deliberate HD withdrawal before death and thus the need for palliative care services for this patient group. Most deaths occurred after an acute clinical decline requiring hospitalization, wherein introduction of palliative services and goals of care assessment often occur late. These observations highlight the importance of early recognition of patients with ESKD on a trajectory of decline who may benefit from advance care planning discussions before they reach the terminal phase. Further studies are needed to assess the effect of palliative care services in this patient population.

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Table 3. Patient characteristics associated with palliative care consultation within 6 months of death, among patients (n=262) who withdrew from hemodialysis before death between 2001 and 2015

Characteristics at Baseline and Death	No Palliative Care Consultation, ^a n=172	With Palliative Care Consultation, ^a n=90	Palliative Care Odds Ratio (95% CI)	P Value
Baseline characteristics				
Age at HD initiation, mean (SD)	75 (11)	72 (13)	0.83 (0.67 to 1.03) ^c	0.09
HD duration, mo, median [IQR]	18 [4–42]	35 [17–57]	1.19 (1.08 to 1.31) ^d	<0.001
Men, n (%)	102 (59)	45 (50)	0.69 (0.41 to 1.15)	0.15
White, n (%)	163 (95)	88 (98)	2.43 (0.51 to 11.49)	0.26
Cause of ESKD, n (%)				0.39
Polycystic kidney disease	1 (0.6)	2 (2)	Reference	
Diabetic kidney disease	64 (37)	37 (41)	0.29 (0.03 to 3.30)	
Hypertension	43 (25)	12 (13)	0.14 (0.01 to 1.67)	
Glomerular/tubulointerstitial disease	22 (13)	15 (17)	0.34 (0.03 to 4.12)	
Acute tubular necrosis	5 (3)	2 (2)	0.20 (0.01 to 3.66)	
Failing kidney transplant	5 (3)	4 (4)	0.40 (0.03 to 6.18)	
Other/unknown	32 (19)	18 (20)	0.28 (0.02 to 3.32)	
Comorbidities and characteristics at death, n (%)				
Congestive heart failure	114 (66)	66 (73)	1.40 (0.80 to 2.46)	0.24
Coronary artery disease	107 (62)	53 (59)	0.87 (0.52 to 1.47)	0.60
Valvular heart disease	96 (56)	45 (50)	0.79 (0.48 to 1.32)	0.37
Diabetes mellitus	96 (56)	48 (53)	0.91 (0.54 to 1.51)	0.70
Malignancy	63 (37)	37 (41)	1.21 (0.72 to 2.04)	0.48
Cerebrovascular disease	73 (42)	46 (51)	1.42 (0.85 to 2.37)	0.18
Liver disease	19 (11)	15 (17)	1.61 (0.78 to 3.35)	0.20
COPD	55 (32)	29 (32)	1.01 (0.59 to 1.75)	0.97
Peripheral vascular disease	75 (44)	40 (44)	1.04 (0.62 to 1.73)	0.90
Depression	74 (43)	45 (50)	1.32 (0.79 to 2.21)	0.28
Hospitalization before death ^b	110 (64)	82 (91)	5.78 (2.62 to 12.73)	<0.001
Hospital location of death (versus nonhospital)	49 (29)	39 (43)	1.92 (1.13 to 3.27)	0.02
P values <0.05 were considered statistically significant and are denoted in bold. P values were derived using logistic regression models. 95% CI, 95% confidence interval; HD, hemodialysis; IQR, interquartile range; COPD, chronic obstructive pulmonary disease.				
^a Palliative care consultations were included if they occurred ≤6 months before death.				
^b Hospitalizations were included if they occurred ≤30 days before death.				
^c Age per 10 years for multivariable analyses.				
^d Per year of HD therapy for multivariable analyses.				

Division of Nephrology on March 11–14 in Long Beach, California, and on March 3–6 2018 in Orlando, Florida.

Study contents are the sole responsibility of the authors and do not necessarily represent the official views of NIH.

Disclosures

A.W.W. is a member of the American Society of Nephrology Public Policy Board.

References

- Findlay MD, Donaldson K, Doyle A, Fox JG, Khan I, McDonald J, Metcalfe W, Peel RK, Shilliday I, Spalding E, Stewart GA, Traynor JP, Mackinnon B; Scottish Renal Registry (SRR): Factors influencing withdrawal from dialysis: A national registry study. *Nephrol Dial Transplant* 31: 2041–2048, 2016
- Davison SN, Jhangri GS, Johnson JA: Cross-sectional validity of a modified Edmonton symptom assessment system in dialysis patients: A simple assessment of symptom burden. *Kidney Int* 69: 1621–1625, 2006
- Chan HW, Clayton PA, McDonald SP, Agar JW, Jose MD: Risk factors for dialysis withdrawal: An analysis of the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry, 1999–2008. *Clin J Am Soc Nephrol* 7: 775–781, 2012
- Redahan L, Brady B, Smyth A, Higgins S, Wall C: The use of palliative care services amongst end-stage kidney disease patients in an Irish tertiary referral centre. *Clin Kidney J* 6: 604–608, 2013
- Wachterman MW, Pilver C, Smith D, Ersek M, Lipsitz SR, Keating NL: Quality of end-of-life care provided to patients with different serious illnesses. *JAMA Intern Med* 176: 1095–1102, 2016
- Grubbs V, Moss AH, Cohen LM, Fischer MJ, Germain MJ, Jassal SV, Perl J, Weiner DE, Mehrotra R; Dialysis Advisory Group of the American Society of Nephrology: A palliative approach to dialysis care: A patient-centered transition to the end of life. *Clin J Am Soc Nephrol* 9: 2203–2209, 2014
- Wachterman MW, Hailpern SM, Keating NL, Kurella Tamura M, O'Hare AM: Association between hospice length of stay, health care utilization, and medicare costs at the end of life among patients who received maintenance hemodialysis [published online ahead of print April 30, 2018]. *JAMA Intern Med* 10.1001/jamainternmed.2018.0256
- United States Renal Data System: *2016 USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States*, Bethesda, MD, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2016
- Hines SC, Glover JJ, Babrow AS, Holley JL, Badzek LA, Moss AH: Improving advance care planning by accommodating family preferences. *J Palliat Med* 4: 481–489, 2001
- Davison SN: End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol* 5: 195–204, 2010
- Wong SP, Kreuter W, O'Hare AM: Treatment intensity at the end of life in older adults receiving long-term dialysis. *Arch Intern Med* 172: 661–663, discussion 663–664, 2012

12. Eneanya ND, Hailpern SM, O'Hare AM, Kurella Tamura M, Katz R, Kreuter W, Montez-Rath ME, Hebert PL, Hall YN: Trends in receipt of intensive procedures at the end of life among patients treated with maintenance dialysis. *Am J Kidney Dis* 69: 60–68, 2017
13. Ellwood AD, Jassal SV, Suri RS, Clark WF, Na Y, Moist LM: Early dialysis initiation and rates and timing of withdrawal from dialysis in Canada. *Clin J Am Soc Nephrol* 8: 265–270, 2013
14. Bajwa K, Szabo E, Kjellstrand CM: A prospective study of risk factors and decision making in discontinuation of dialysis. *Arch Intern Med* 156: 2571–2577, 1996
15. Mailloux LU, Bellucci AG, Napolitano B, Mossey RT, Wilkes BM, Bluestone PA: Death by withdrawal from dialysis: A 20-year clinical experience. *J Am Soc Nephrol* 3: 1631–1637, 1993
16. Feely MA, Hildebrandt D, Edakkanambeth Varayil J, Mueller PS: Prevalence and contents of advance directives of patients with ESRD receiving dialysis. *Clin J Am Soc Nephrol* 11: 2204–2209, 2016
17. Hickson LJ, Chaudhary S, Williams AW, Dillon JJ, Norby SM, Gregoire JR, Albright RC Jr., McCarthy JT, Thorsteinsdottir B, Rule AD: Predictors of outpatient kidney function recovery among patients who initiate hemodialysis in the hospital. *Am J Kidney Dis* 65: 592–602, 2015
18. Schoonover KL, Hickson LJ, Norby SM, Hogan MC, Chaudhary S, Albright RC Jr., Dillon JJ, McCarthy JT, Williams AW: Risk factors for hospitalization among older, incident haemodialysis patients. *Nephrology (Carlton)* 18: 712–717, 2013
19. Hickson LJ, Negrotto SM, Onuigbo M, Scott CG, Rule AD, Norby SM, Albright RC, Casey ET, Dillon JJ, Pellikka PA, Pislaru SV, Best PJM, Villarraga HR, Lin G, Williams AW, Nkomo VT: Echocardiography criteria for structural heart disease in patients with end-stage renal disease initiating hemodialysis. *J Am Coll Cardiol* 67: 1173–1182, 2016
20. Delva O, Campbell F: Measuring your clinic's performance with CROWNWeb. *Dial Transplant* 39: 395–396, 2010
21. The Centers for Medicare & Medicaid Services. Details for ESRD Death Notification Form CMS 2746. Available at: <https://www.cms.gov/Medicare/CMS-Forms/CMS-Forms/CMS-Forms-Items/CMS008869.html>. Accessed on May 1, 2018
22. Murphy E, Germain MJ, Cairns H, Higginson IJ, Murtagh FE: International variation in classification of dialysis withdrawal: A systematic review. *Nephrol Dial Transplant* 29: 625–635, 2014
23. Feely MA, Swetz KM, Zavaleta K, Thorsteinsdottir B, Albright RC, Williams AW: Reengineering dialysis: The role of palliative medicine. *J Palliat Med* 19: 652–655, 2016
24. Yong DS, Kwok AO, Wong DM, Suen MH, Chen WT, Tse DM: Symptom burden and quality of life in end-stage renal disease: A study of 179 patients on dialysis and palliative care. *Palliat Med* 23: 111–119, 2009
25. Wetmore JB, Yan H, Hu Y, Gilbertson DT, Liu J: Factors associated with withdrawal from maintenance dialysis: A case-control analysis [published online ahead of print January 10, 2018]. *Am J Kidney Dis* 10.1053/j.ajkd.2017.10.025
26. Renal Physician Association: *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, Rockville, MD, Renal Physician Association, 2010
27. Schell JO, Cohen RA: A communication framework for dialysis decision-making for frail elderly patients. *Clin J Am Soc Nephrol* 9: 2014–2021, 2014
28. Thorsteinsdottir B, Swetz KM, Albright RC: The ethics of chronic dialysis for the older patient: Time to reevaluate the norms. *Clin J Am Soc Nephrol* 10: 2094–2099, 2015
29. Kurella Tamura M, Montez-Rath ME, Hall YN, Katz R, O'Hare AM: Advance directives and end-of-life care among nursing home residents receiving maintenance dialysis. *Clin J Am Soc Nephrol* 12: 435–442, 2017
30. Birmelé B, François M, Pengloan J, François P, Testou D, Brillet G, Lechapois D, Baudin S, Grezard O, Jourdan JL, Fodil-Cherif M, Abaza M, Dupouet L, Fournier G, Nivet H: Death after withdrawal from dialysis: The most common cause of death in a French dialysis population. *Nephrol Dial Transplant* 19: 686–691, 2004
31. Sekkarie MA, Moss AH: Withholding and withdrawing dialysis: The role of physician specialty and education and patient functional status. *Am J Kidney Dis* 31: 464–472, 1998
32. Cohen LM, Germain MJ, Poppel DM, Woods AL, Pekow PS, Kjellstrand CM: Dying well after discontinuing the life-support treatment of dialysis. *Arch Intern Med* 160: 2513–2518, 2000
33. O'Connor NR, Dougherty M, Harris PS, Casarett DJ: Survival after dialysis discontinuation and hospice enrollment for ESRD. *Clin J Am Soc Nephrol* 8: 2117–2122, 2013
34. Cohen LM, McCue JD, Germain M, Kjellstrand CM: Dialysis discontinuation. A 'good' death? *Arch Intern Med* 155: 42–47, 1995
35. Neely KJ, Roxe DM: Palliative care/hospice and the withdrawal of dialysis. *J Palliat Med* 3: 57–67, 2000
36. Murray AM, Arko C, Chen SC, Gilbertson DT, Moss AH: Use of hospice in the United States dialysis population. *Clin J Am Soc Nephrol* 1: 1248–1255, 2006
37. Murtagh FE, Addington-Hall JM, Higginson IJ: End-stage renal disease: A new trajectory of functional decline in the last year of life. *Am J Geriatr Soc* 59: 304–308, 2011
38. Ceckowski KA, Little DJ, Merighi JR, Browne T, Yuan CM: An end-of-life practice survey among clinical nephrologists associated with a single nephrology fellowship training program. *Clin Kidney J* 10: 437–442, 2017
39. Holley JL, Carmody SS, Moss AH, Sullivan AM, Cohen LM, Block SD, Arnold RM: The need for end-of-life care training in nephrology: National survey results of nephrology fellows. *Am J Kidney Dis* 42: 813–820, 2003
40. van Biesen W, van de Luijngaarden MW, Brown EA, Michel JP, van Munster BC, Jager KJ, van der Veer SN: Nephrologists' perceptions regarding dialysis withdrawal and palliative care in Europe: Lessons from a European Renal Best Practice survey. *Nephrol Dial Transplant* 30: 1951–1958, 2015
41. Rabow MW, O'Riordan DL, Pantilat SZ: A statewide survey of adult and pediatric outpatient palliative care services. *J Palliat Med* 17: 1311–1316, 2014
42. Leggat JE Jr., Bloembergen WE, Levine G, Hulbert-Shearon TE, Port FK: An analysis of risk factors for withdrawal from dialysis before death. *J Am Soc Nephrol* 8: 1755–1763, 1997

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